Effect of Ethnicity and Parental Illness Representation on Complementary and Alternative Medicine Usage and Asthma Control in Childhood Asthma

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Chapter I

Introduction

Racial and ethnic disparities in asthma health outcomes have been increasing in the United States. Minority children use controller medication less often, have less continuity of care, and visit emergency departments more frequently than their non-minority counterparts (Canino et al., 2006; Essien, Mobley, Griffith, Creer, & Geller, 2001; Lara, Akinbami, Flores, & Morgenstern, 2006). Asthma prevalence has been increasing particularly in Latino children (Akinbami & Schoendorf, 2002). According to U.S. Census Bureau population estimates as of July 1, 2013, there are roughly 54 million Hispanics living in the United States, representing approximately 17% of the U.S. total population, making people of Hispanic origin the nation's largest ethnic or race minority. Of Latinos in the United States, 73% are of Mexican or Puerto Rican descent (US Census Bureau, 2010). While these groups share similar cultures, significant heterogeneity exists. Recent descriptive research has confirmed differences in asthma prevalence, mortality and morbidity, illness beliefs, and healthcare practices in Latino subgroups. Puerto Ricans (PR) exhibit the highest rates of asthma in all ethnic groups, while Mexicans exhibit the lowest rates (Akinbami et al., 2012).

Complementary and alternative medicine (CAM) is utilized by 33% to 89% of children with current asthma (Slader, Reddel, Jenkins, Armour, & Bosnic-Anticevich, 2006).

There are particularly high rates of CAM usage in the Latino population. In one study, seventy-two percent of Hispanic mothers reported substituting alternative medications (folk remedies) for prescription asthma medications for their child (Adams et al., 2007). Parents use CAM for a variety of reasons, such as (1) folk beliefs, (2) distrust of medical providers, (3) lack of medical information, (4) fear of medication side effects and dependence, (5) cost barriers, and (6) illness that does not seem managed by medical treatments (Sidora-Arcoleo, 2011). With CAM usage so high, especially in Latino children with asthma, we must work to understand it.

The role of culture, acculturation, and illness representations (the way the parent interprets health and illness which influences how the child's asthma is managed) in treatment decisions is an understudied but important factor in asthma research. Parental illness representations (IRs) may account for differences in the use of complementary and alternative medicine (CAM) and controller medication usage.

Background

Today, one in 11 children have an asthma diagnosis in the United States. One in two children with asthma will have an asthma attack each year (CDC Asthma's Impact on the Nation, 2013), resulting in 10.5 million missed days of school (Moorman, Akinbami, Bailey, et al. 2012) and 335,000 hospitalizations per year which account for 13.5% of all pediatric hospital stays (excluding newborns) (Merrill, Stranges, &Steiner, 2008). Nearly one in five

children with asthma went to an emergency department for care in 2009 (CDC Asthma's Impact on the Nation, 2013). 157 children under 15 died of asthma in 2009, each one a preventable death with education and appropriate medication (CDC Compressed Mortality File 2012). Asthma results in a large burden on the healthcare system; asthma costs the United States $56 billion each year (CDC Asthma's Impact on the Nation, 2013).

In the last decade, the prevalence of asthma in the United States has increased by nearly 15% (CDC Asthma's Impact on the Nation, 2013). Particularly concerning is the asthma prevalence disparity between ethnicities: 7.7% of whites have been diagnosed with asthma, compared to 11.2% of blacks, and 6.5% of Hispanics. Despite the low prevalence in Hispanics as a whole, the statistics for different Latino subgroups tell a different story. Sixteen percent of PR have asthma, compared to only 5.4% of Mexicans (Moorman, Akinbami, Bailey, et al. 2012). This study will delve into CAM prevalence in children with asthma, parental IRs, and asthma control in PR and Mexicans, with the goal of gaining understanding about the differences between the two ethnic groups.

Purpose of Study

The purpose of this study is to explore lifetime and current prevalence of CAM usage, parental illness representations (IR) around asthma, ethnic differences between Mexicans and PR for CAM use and IRs, and clinician-rated asthma control. The role of parental IR in CAM use and asthma control will be explored. This study will look at how

these variables interact with each other to explore the influence of parental IRs on CAM use, how use of CAM affects asthma control and if these relationships differ by ethnicity. The results of this study will impact our understanding of the ethnomedical beliefs of diverse groups of Latino parents and their treatment decisions so that tailored interventions can be developed to arrive at a shared decision-making plan that is sensitive to these beliefs and practices while ensuring optimal asthma management.

Significance of Study

The significance of this study is the knowledge it brings about the diversity within the Latino population, CAM, and childhood asthma. As medicine trends towards increased self-management of illnesses, it is especially important to understand how caregivers perceive their child's asthma, and their beliefs towards the medical treatment model and ethnomedical beliefs, so that shared and appropriate decision making can occur. It is important to understand IRs and beliefs about CAM, so effective communication and shared decision-making can occur. Healthcare providers who are familiar with and sensitive to IRs and care needs of diverse groups can play a decisive role in improving health outcomes of patients with asthma by heightened awareness of and respect for cultural differences among the children and families with whom they interact. To develop effective interventions that target asthma health disparities, we must first understand the

characteristics of these groups and how they interact to impact parental IRs, CAM usage, and asthma control.

Conceptual Frame of Reference (Theoretical Framework)

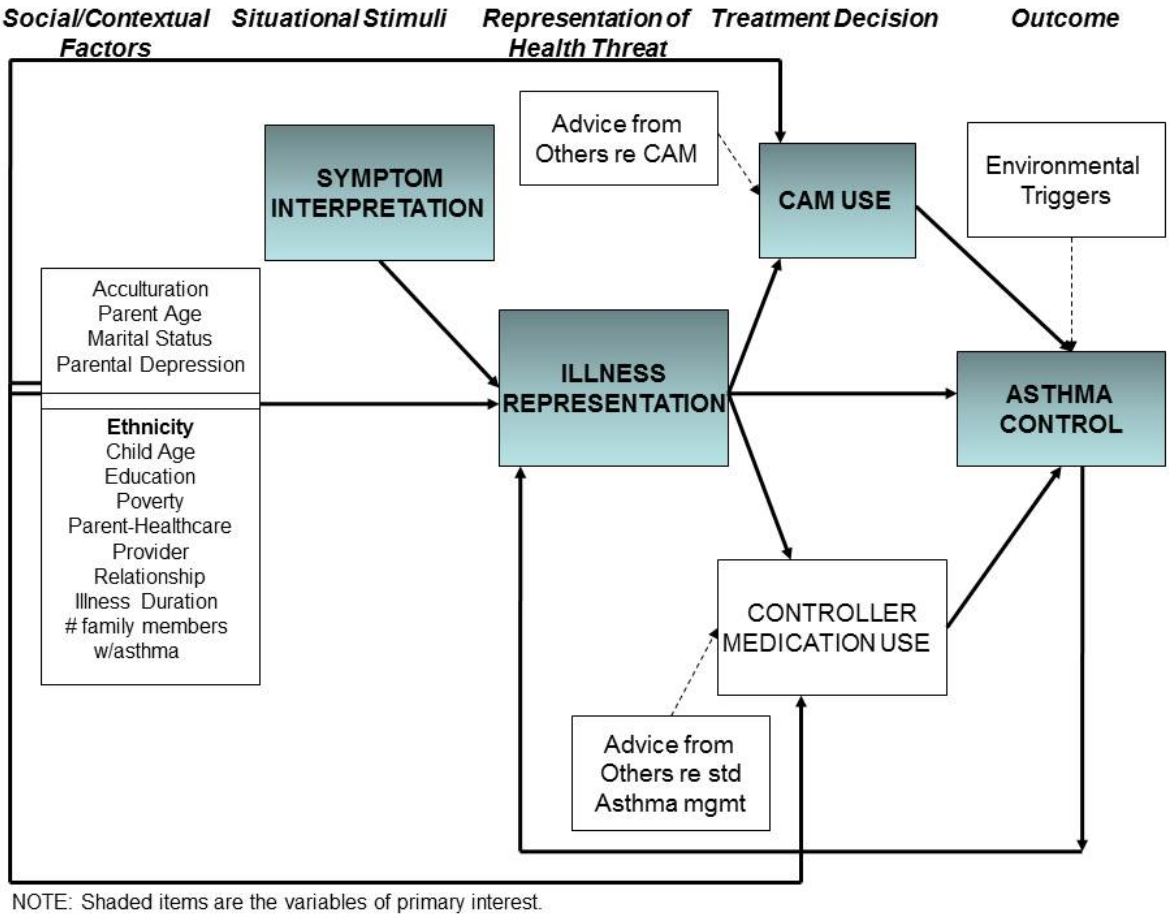
The Common Sense Model of Illness Representation provides the theoretical framework for investigating the disparities in asthma control through the pathways of parental IR and the use of CAM and controller medications (Cameron, Leventhal, 2003; Leventhal, Benjamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller, et al., 1997). The model describes a cognitive processing system that includes situational stimuli (perception of the child's symptoms), objective representation of the health threat (illness representation) with its treatment decisions (CAM and controller medication use) and appraisal of the outcomes (asthma control) for the success or failure of the treatment decisions. A feedback loop is included in the model with IRs potentially changing over time as the parents gain experience managing their child's asthma (Diefenbach, Leventhal, 1996). The model has three tenets: (1) the parent is an active problem solver; (2) the IR is the central cognitive contrast that drives the parents' treatment decision and appraisal of the outcomes; and (3) IRs are personalized and may not be in agreement with the medical facts (Diefenbach, Leventhal, 1996; Leventhal, Leventhal, Contrada, 1998). A parent's IR, treatment decision, and interpretation of outcomes are influenced by the parent's personality traits, prior history managing their child's asthma, and cultural and social contexts. The social and cultural contexts where a person lives play an important role in

illness representation in two ways: "1) culture provides the labels for categorizing the events/symptoms that define illness and ensures culturally common views of a given disease or illness; and 2) culture provides social and personal contacts that the parent then uses in constructing the IR and also in developing the action plan for coping with the disease threat" (Leventhal, Leventhal, Contrada, 1998, p728). When parents have prior experience in managing their child's asthma, they have a stored memory of the treatments they perceived were successes or failures, which then influence how the parent perceives the child's symptoms for the current episode and that treatment decision. There are five distinct features of illness representation:

1. Identity: the disease label and the somatic symptoms the parent associates with the disease.
2. Cause: the parent's ideas about what causes the disease.
3. Consequences: the parent's perceived short and long term effects of the disease, and the physical, social, emotional, and economic ramifications of the disease.
4. Time-line; the parent's expectations about the disease duration; acute, chronic, or episodic/cyclical.
5. Controllability; the parent's ideas about cure or recovery either through their own actions or medical intervention (Diefenbach & Leventhal, 1996).

The strengths of the Common Sense Model of Illness Representation are that it includes (1) a longitudinal analysis of the sociodemographic, cultural, experiential, and environmental

influences on parental illness representations; (2) how parental IRs impact use of CAM and controller medications; (3) how these treatment decisions affect asthma control; and (4) through a feedback loop, how resulting asthma symptom control reshapes parent's illness representations (Figure 1).



NOTE: Shaded items are the variables of primary interest.

Research Questions

RQ1.What is the lifetime and current prevalence of CAM for children with asthma use in this sample?

RQ1a. Does current CAM use differ by ethnicity?

RQ1b. Do parents report using CAM with (complementary) or instead of (alternative) their child's controller medications?

RQ2. Do parents' asthma illness representations predict treatment decisions (CAM and controller medication use) and clinician rated asthma control after controlling for caregiver depression and symptom perception?

RQ2a. Are there differences in treatment decisions and clinician-rated asthma control by ethnicity?

Chapter II-Literature Review

Prevalence of CAM Usage

CAM is utilized by 33% to 89% of children with current asthma (Slader, Reddel, Jenkins, Armour, & Bosnic-Anticevich, 2006). The National Institutes of Health defines complementary and alternative medicine (CAM) as "medical products and practices that are not part of standard care" (Complementary and Alternative Medicine, 2014). Standard care is what licensed health professionals, such as doctors and nurses, provide. Complementary medicine is practiced *with* standard medical care. Alternative medicine is used *instead of* standard medical care (Complementary and Alternative Medicine, 2014).

Forty-four percent of parents in a study done in the Bronx, New York used CAM as the first line of treatment for an asthma attack. Seventy-two percent of Hispanic mothers reported substituting alternative medications (folk remedies) for prescription asthma medications for their child (Adams et al., 2007). However, prescription medication adherence and CAM usage in Latinos are not correlated, suggesting that the two share a complex relationship that may change with time, acculturation, and financial stability (McQuaid, Fedele, Adams, Koinis-Mitchell, Mitchell, Kopel, & Canino, 2014). Conversely, in Non-Latino Whites, medication adherence and CAM usage were positively correlated, suggesting that some families with the resources to try every option available to control their child's symptoms will often do so (McQuaid, Fedele, Adams, Koinis-Mitchell, Mitchell,

Kopel, & Canino, 2014). Despite the high usage and faith in CAM, only 18% of parents reported CAM usage to the physician (Braganza, Ozuah, & Sharif, 2003). The most common CAM techniques were prayers, rubs, massage, honey, and oils. CAM usage is most common in children with mild to moderate persistent asthma compared to children with mild intermittent and severe persistent asthma (Sidora-Arcoleo, Yoos, McMullen, & Kitzman, 2007). Socioeconomic status also greatly affected CAM usage; 80% of poor parents utilized CAM versus 63% of non-poor parents (Sidora-Arcoleo et al., 2007). In a study of CAM usage in Latino children with asthma, it was found that lower acculturation is associated with higher rates of CAM usage (McQuaid, et al., 2014). Children whose parents have positive beliefs about CAM are more likely to have poorly controlled asthma (Adams, Murdock, & McQuaid, 2007).

Parent perception of CAM effectiveness is also important. Fifty-nine percent of parents of children with asthma believe that CAM usage is just as effective as conventional medications in controlling their child's asthma. Inability to afford prescriptions, language barriers, and transportation issues may lead parents to utilize easily accessible CAM therapies instead of prescription medications (Adams et al., 2007). Endorsement of CAM and parental preference for CAM in lieu of prescribed medication may be due to barriers to healthcare and/or cultural beliefs for minority and poor families.

Cultural Beliefs, Ethnicity and CAM Usage

Health beliefs are connected to culture, social class, education, and minority status. IRs are influenced by cultural context, and a person's culture and health beliefs influence whether parents would utilize CAM for their child with asthma. In a study of Chinese Americans, health beliefs and acculturation were found to be the most significant enablers for CAM usage (Wu, 2004). A lack of understanding of asthma can lead to CAM usage and poor medication adherence. Sixty percent of Dominican mothers of children with asthma thought that the child did not have asthma when they were not experiencing an acute episode. More than 80% of these Dominican mothers feared medication dependence, distrusted the doctor to disclose side effects, and though that "people in this country take to many medicines" (Bearison, Minian, & Granowetter, 2002). Seventy-one percent of caregivers of children with asthma voiced concern about the safety of prescription asthma medications. Despite high rates of CAM, 77% of caregivers considered herbal remedies to be safe and were unaware of any medication interactions (George & Topaz, 2013). A patient's health beliefs can lead to a lack of understanding of the disease and its medical treatments, which is critical for treatment adherence.

Religion and spirituality influence CAM usage. Because religion and spirituality are part of a person's culture and very frequently influence health care decisions (i.e. abortion, blood transfusions, end-of-life care), it is clear that they would influence CAM usage (Koenig, 2004). In a study of Asian-Americans, it was found that increased spirituality was

universally associated with higher rates of CAM usage (Hsiao, et al., 2006). It was reported in a study among Korean Americans that "philosophical congruence" was the main reason people used alternative therapies; that is, the therapies were more in line with their values, world views, and religious/spiritual philosophies (Kim & Chan, 2004).

Hsiao, Wong, Goldstein, Yu, Andersen, Brown, and Wenger (2006) found that the type of CAM use varies by ethnicity. In their study, they found 68.6% of Asian-Americans used Asian-specific CAM (acupuncture, traditional Chinese medicine practitioner, green tea, or soy products), 16.2% of American Indians used American Indian-specific CAM (native American healers or healing rituals), 48% of African Americans used specific CAM (others pray for your health or garlic), 2.9% of Latinos used Latino-specific CAM (included only use of a curandero), and 29.7% of whites used white-specific CAM (massage or osteopathy). The results of these studies demonstrate that different cultures utilize and endorse different CAM modalities. Practitioners should be aware of different CAM modalities because they may potentially interact with medications and the medical treatment regimen.

The Latino population is very diverse, and each group within the population has unique characteristics and beliefs. CAM is known as "folk medicine" to many Latinos, and if frequently practiced by lay practitioners. In the Mexican culture, *curanderos* are more common; whose treatment is often a combination of herbal remedies, prayer, and dramatic

healing rituals (Perez-Stable & Salazar, 2004). In the Latino population, the humoral imbalance of hot and cold is often thought to be the root of disease. Asthma is believed to be a cold disease; therefore Latinos frequently endorse CAM activities that restore warmth (Bearison, Minian, & Granowetter, 2002). In a study of Hispanic mothers of children with asthma, 76% of mothers said dressing warmly was important to prevent asthma attacks and 76% attributed the cause of their child's asthma attack was children's teacher allowing them outside in cold weather. In a study of island PR parental caregivers, 84% believed "getting wet while sweating" could lead to asthma symptoms (Koinis-Mitchell, McQuaid, Canino, et al., 2008). Common "warm" therapies to combat a "cold" illness like asthma are: whale oil, cod liver oil, honey, garlic, and onion (Bearison, Minian, & Granowetter, 2002). Similarly, in a study of PR parents of children with asthma, it was found that 88% of PR parents in Rhode Island and 96% of mainland PR parents believed strong emotions (good or bad) led to an asthma attack (Koinis-Mitchell, McQuaid, Canino, et al., 2008). The three most common behavioral strategies to manage asthma by PR are dress warm, stay calm, and use a humidifier. 92% of study participants used these strategies or deemed them effective (Zayas, Wisniewski, Cadzow, & Tumiel-Berhalter, 2011). Latinos often hold different beliefs regarding the etiology of asthma and that greatly influences CAM usage.

Chapter III

Methodology

Research Design

This study is a secondary data analysis of the baseline data from a longitudinal study of parental illness representations, CAM and controller medication use among a diverse sample of 536 Latino parents and their children with asthma aged 5-12 years (primarily Mexican and PR). Parents were interviewed with a structured format and shorter interviews were conducted with the children. Objective measures of children's lung function were obtained, as well as a 12 month retrospective review of the children's medical records for prescribed medications and asthma-related healthcare utilization. Interviews and assessments were conducted at enrollment, and months 3, 6, 9, and 12 post-enrollment. Chi-square, t-tests, and regression analyses were conducted.

Population and Sample Design

Baseline data were collected from 536 Mexican and PR caregivers and their children, ages 5-12, who had asthma requiring the daily use of controller medications. This population was chosen based on the presumption that children in this age range do not manage their own asthma; they are still heavily dependent on their caregivers. Families were recruited from clinics in Phoenix, Arizona and Bronx, New York where there are higher populations

of inner-city poor Mexican and PR children with asthma. It was necessary to enroll multiples sites in this study, in order to obtain a sufficient number of families, particularly of Mexican and PR descent, to participate and conduct the study. A description of each site is presented below.

The Neighborhood Action Outreach for Health (NOAH) program, administered by the Scottsdale Healthcare organization (SHC), provides primary care services, preventive healthcare, and immunizations for uninsured and under-insured children and families through a mobile unit and two school-based health clinics. Approximately 3,248 children receive urgent primary care services, 647 children receive routine, preventive primary care services, and 1,383 dental visits are provided through the NOAH health centers annually. The NOAH nurse practitioners and medical staff provide health education to parents through counseling, exhibits, and health screenings for diabetes, asthma, blood pressure, vision, and hearing. Well-child checks and sports physicals are also performed at NOAH sites. These clinics primarily serve low-income Mexican families with no health insurance. Approximately 22% of the children served have a diagnosis of asthma. Dr. Sidora-Arcoleo purchased and installed spirometry equipment in each of the clinics and trained the staff on how to use it in 2007. These clinics now incorporate asthma screening procedures per the NAEPP's Expert Panel Report clinical guidelines (U.S. Department of Health & Human Services: National Asthma Education Program. Expert panel 3 report: Guidelines for the diagnosis and management of asthma. Bethesda, MD: U.S. Department of Health & Human

Services; 2007) and it is anticipated that their reported asthma prevalence rate will increase due to enhanced detection.

The Phoenix Children's Hospital (PCH) Breathmobile is a self-contained mobile asthma clinic that travels to inner-city schools providing asthma identification, teaching, treatment, and follow-up. Since the inception of the Breathmobile, there has been a (1) greater than 40% reduction in missed school days and (2) greater than 70% percent reduction in emergency room visits due to asthma-related problems, and (3) greater than 73% decrease in asthma-related hospital stays among Breathmobile patients. The Breathmobile visits 19 schools in South Phoenix, where children are more likely to be uninsured due to low socioeconomic status. The service requires no referral and there is no charge for treatment. Once diagnosed, the children receive an asthma action plan that includes education for asthma self-management, follow-up appointments and evaluations, controller medications, and a 24-hour phone number in case questions arise. The Breathmobile staff sees an average of 70 school-aged patients/week and includes a pediatric nurse practitioner, a registered nurse, a respiratory therapist, and an operations coordinator. Seventy-seven percent of the population served is Latino (primarily Mexican), 13% black, and 5% white.

The pediatric clinic at Jacobi Medical Center (JMC) in Bronx, NY serves an ethnically diverse group of children who have a broad range of asthma severity. At JMC, there are

approximately 2,634 visits to the Pediatric Asthma Clinic, 2,507 visits to the Pediatric Allergy Clinic, 40,535 visits to the General Pediatrics Clinic, and 3,182 asthma-related emergency room visits per year. The racial/ethnic breakdown of asthma visits at JMC is 51% Latino (of those 48% are PR) and 30% Black/African-American.

Data Collection Procedures

To be eligible for the study, children must have met the following criteria: a) The child had to be between the ages of 5 and 12; b) had a diagnosis of asthma as obtained from their medical record; c) identified as Latino as described by the child's primary care caregiver; d) had no other significant pulmonary complications or conditions; e) participating parent must have had the majority responsibility for the child's day-to-day asthma management and care; and f) no cognitive learning disability that would interfere with the parent or child's ability to participate in the interview process. Electronic health records within each recruitment site were used to identify patients who fit the specified diagnosis, ethnicity, and age. Eligible families were recruited through face-to-face invitations during clinic visits, by mailing recruitment letters from the health care provider to potential families, and by making phone calls inviting families to participate. The research nurse/assistant (RNA) at each practice site explained the study and reviewed eligibility criteria with each family before obtaining verbal assent to participate. An appointment was then made for the parent and child to complete the informed consent,

child verbal assent, interviews, and spirometry tests. All materials were made available in both English and Spanish.

The RNA conducted a structured interview with the parent that included the Asthma Illness Representation Scale (AIRS©) and Parent/Health Care Provider Relationship Scale (Sidora-Arcoleo, Feldman, Serebrisky, Spray, 2010a; Sidora-Arcoleo, Feldman, Serebrisky, Spray, 2010b), Parent-Childhood Asthma Symptom Checklist (Fritz, G.K., McQuaid, E.L., Spirito, A., Klein, R.B., 1996; Fritz, G.K., Overholser, J.C., 1989), Asthma Trigger Inventory (Ritz, Steptoe, Bobb, Harris, Edwards, 2006) and Stephenson Multigroup Acculturation Scale (Stephenson, 2000) as well as information regarding demographics, parent-reported and clinician-rated asthma control, prescribed controller medications, and any alternative therapies that are currently being used. Interviewers conducted the interview in either English or Spanish based on the parent's preference, and each took approximately 60 to 90 minutes. Interviews were completed at enrollment and 3, 6, 9, and 12 months post-enrollment.

Child interviews and spirometry maneuvers were done independently of the parent interviews. Spirometry -a medical test that measures how well your lungs work by measuring how much you inhale and exhale and how quickly you exhale - was done per the guidelines set forth by the American Thoracic Society (1995), and the child continued to use his/her prescribed medications prior to any tests. The interview with the child

included the Asthma Control Test (Nathan, R.A., Sorkness, C.A., Kosinski, M., Schatz, M., Li, J.T., Marcus, P., et al., 2004; Liu, A.H., Zeiger, R., Sorkness, C., Mahr, T., Ostrom, N., Burgess, S., et al., 2007) and the Childhood Asthma Symptom Checklist (Fritz, G.K., McQuaid, E.L., Spirito, A., Klein, R.B., 1996; Fritz, G.K., Overholser, J.C., 1989) in order to assess the child's reports of symptoms during asthma exacerbations. Interviews were conducted in Spanish or English based on the child's preference and took approximately 20 to 30 minutes. The spirometry assessment took place after the interview. Children completed interviews and assessments on the same schedule as the parents. Since the children interviews were shorter than the parent interviews, a play area was available to the children at each site. The children completed the interview and spirometry assessment at enrollment and 3, 6, 9, and 12 months post-enrollment.

At the 12-month assessment period, information was abstracted from the child's medical record regarding age, gender, health insurance, number and types of visits for asthma-related healthcare, asthma medications prescribed and/or discontinued at each visit, spirometry readings, and any notes regarding use of alternative therapies from enrollment through the 12-month assessment date.

Data Collection Instrument

The parent interviews utilized many different screening tools and questionnaires. Portions of the interview that are relevant to this research are:

Ethnicity: Parents were asked to identify which ethnicity they most closely identified with. Their options were Mexican, Puerto Rican, Cuban, Dominican, Hispanic, South American, Central American, and Other. Parents were also asked to give their country of birth.

Illness Representations: IRs are measured using the five subscales of the AIRS© and the total score. This instrument is designed to identify barriers and risk factors for under-utilization of controller medications. The English version of the AIRS© tool was developed and validated among an ethnically diverse sample {{451 Yoos,H.L. 2003; 292 Yoos, H.L. 2007; 1017 Sidora-Arcoleo, K. 2010}}. The five subscales of the AIRS© are: (1) treatment expectations (8 items, α=0.75); (2) attitudes towards medication use (8 items, α=0.78); (3) facts regarding asthma (11 items, α=0.71); (4) the nature of asthma symptoms (5 items, α=0.61); and (5) emotional aspects of medication use (5 items, α=0.55). The Cronbach's alpha for the overall scale score was 0.84 (Sidora-Arcoleo, Feldman, Serebrisky, Spray, 2010a; Yoos et al., 2007). Each item is scored on a 5-point Likert-type scale with 1=strongly agree to 5=strongly disagree. When necessary, items within each subscale are reverse scored so that higher values indicate closer alignment with the professional model for asthma management. The subscale and total score are calculated as the mean of the non-

missing items. The scale has been translated to Spanish following accepted translation/back-translation methodology and was validated among a sample of Mexican and PR families by Drs. Sidora-Arcoleo & Feldman (Sidora-Arcoleo, Feldman, Serebrisky, Spray, 2010b).

Clinician-rated Asthma Control: Asthma symptom control will be assessed through the parent and child interviews and child spirometry assessment per the National Asthma Education and Prevention Program's Expert Panel Reports clinical guidelines (U.S. Department of Health & Human Services, 2007). The guidelines state that an assessment of severity is conducted for children not currently on long term control medications and that once therapy is initiated, an assessment of control is completed. There are four severity groups (1) intermittent, (2) mild persistent, (3) moderate persistent, and (4) severe persistent and three control groups (1) well-controlled, (2) not well controlled, and (3) very poorly controlled. Pediatric pulmonologists Dr. Radford (Phoenix) and Dr. Serebrisky (Bronx) assigned the child's severity or control level, as appropriate, based on the parent's and children's responses to structured questions regarding daytime symptoms, nocturnal symptoms, activity limitations, use of short-acting β2 agonists for the 2-4 week period prior to the interview, and lung function tests conducted during the child's portion of the interview per the 2007 NAEPP Expert Panel Report Guidelines (U.S. Department of Health & Human Services, 2007). We created a dichotomous variable representing to express asthma control, specifically well-controlled yes(Y) or no (N).

Subjective Report of Asthma Control: The children completed the Asthma Control Test (ACT), which is a short (5-7 items depending on age), validated instrument for assessing asthma control. The original ACT was developed, tested, and validated for use in subjects age 12 years and older (Nathan et al., 2004). The ACT instrument exhibits good reliability and validity as a short screening tool. The items consist of a subjective assessment of control and frequency estimates of how often asthma keeps the respondent from getting things done, how often the respondent had shortness of breath and nighttime awakenings, and how often the respondent had to use an inhaler or nebulizer. Cronbach's alpha=0.84 and the ACT demonstrated a significant correlation with specialists' assessment of control (r=0.45, p=0.0001). Overall agreement with the specialists' rating of control was 74.1% (Nathan et al., 2004). Scores < 19 are indicative of poorly controlled asthma. A version for children ages 4-11 years (C-ACT) has been developed and validated (Liu et al., 2007). This is a seven-item instrument with four items completed by the child: (1) how is your asthma today, (2) do you cough because of asthma, (3) do you wake up at night because of your asthma, and (4) is asthma a problem when you run, exercise, or play sports, and three items by the caregiver: frequency in the past 4 weeks of daytime symptoms, wheeze, and nighttime awakenings). Potential scores range from 0-27. Cronbach's alpha=0.79 and the C-ACT exhibited moderate to strong correlations with parent and child quality of life measures (r=0.47, r=0.68, respectively). A cut point of < 19 indicates poorly controlled asthma and correctly classifies children 72% of the time(Liu et al., 2007). The ACT has

undergone Spanish linguistic translation and validation and has been shown to be a reliable and valid Spanish-language instrument for assessing control. Cronbach's alpha was 0.84 and the intra-class correlation coefficient was 0.85. Higher ACT scores were negatively related to exacerbations and positively related to lower symptom frequency and intensity. Sensitivity and specificity were 71.3% and 85.4%, respectively. Consistent with the original version, a score > 19 classifies asthma symptoms as "well-controlled." Scores of 12-19 indicate "not well-controlled" asthma symptoms and scores <12, "very poorly controlled" asthma symptoms (Vega et al., 2007). A validated Spanish version of the C-ACT is not available, thus the C-ACT was translated/back-translated per accepted methodology. The sample for this study ranged in age from 5-12, therefore the age-appropriate version was administered.

CAM: The parent interviews included a single, global question about CAM use and also structured questions regarding specific CAM therapies in treatment of their child's asthma. Parents were asked, "Have you ever tried medications or treatments other than those prescribed by your doctor to manage your child's asthma?" If yes, they were then asked to list what they used. The next set of questions asked whether they used certain types of CAM treatments, such as herbal supplements, herbal teas, special foods, vitamins, massage, reflexology, prayer, breathing exercises, rubs, syrups, acupuncture, breathing exercise, or spinal manipulation. If the parents answered yes to any of the above treatments, they were asked if they use them instead of or along with prescribed medications, and whether they

have told their child's healthcare provider about them. If they have discussed these treatments with the healthcare provider, they were asked what the provider's response was. If they did not discuss them with the child's healthcare provider, they were asked why not. Several CAM variables were created. Dichotomous variables for any lifetime or current CAM use (Y/N) and a composite CAM variable was created for analysis. The composite variable had 4 levels:

- No CAM and no controller/anti-inflammatory
- No CAM, controller only
- CAM only, no controller
- CAM and controller

Data Analysis

Eligible participants who declined to participate were compared with those enrolled on demographic characteristics to check for sample bias. Descriptive statistics identified the distribution of data and total instrument scale scores for each of the study surveys. T-tests were examined for continuous variables and chi-square tests for categorical variables addressing RQ1, RQ1a and RQ1b. Multinomial logistic regression was used to assess RQ2 and RQ2a.

Non-normal Distributions: Full attention was given to the distributional properties of variables and to regression diagnostics. We made appropriate adjustments for outlying data points.

Level of Significance

The level of significance used is $p<.05$.

Chapter IV

Results

This chapter will present the findings of this research study. The chapter will include multiple statistical tables.

Response Rate of the Sample/Population

Table 1 presents the enrollment data. Although 12 months of data were collected, only the baseline data were used in this project. The overall attrition rate was 17.6%. This is lower than the 20% estimated for the power calculations. When we examined attrition by site, we discovered that the rates were quite low at both Phoenix sites (5.7% at the school-based health clinics and 6.7% at the Breathmobile). The higher than anticipated attrition rate in New York, 33.3% occurred due to four natural disasters which occurred in a 2 year period. There was hurricane Sandy, two blizzards, and a power failure. A number of our families were displaced from their homes when the hurricane hit and ended up moving out of the area.

Table 1. Enrollment Table

Site	A. Total Enrolled	B. # of Dropouts	C. Adjusted Total of Enrolled (A-B=C)	D. # of Dropouts that completed 3+ interviews	E. # of "past due" families that have completed at least 3 interviews
PCH	105	7	98 (148, PCH+SHC)	0	1
SHC	53	3	50	1	2
Jacobi	110	34	72	8	9
Total	268	48	220	9	12

- PCH: Phoenix Children Hospital
- SHC: Scottsdale Healthcare
- Jacobi: Jacobi Medical Center

Representativeness of Sample

The population in Phoenix, AZ is very diverse socioeconomically and thus, the sample recruited here was not representative of the population regarding education and poverty level. Our families, on average, had lower education levels and more were classified as living in poverty. The average adult age was comparable. The sample recruited from the Bronx was representative of the Bronx population as whole based on caregiver's age, education level, and poverty status (data not shown).

Table 2. Profile of Sample/Population

Sample Baseline Characteristics

Variable	**Mexican (*N*=189)**	**Puerto Rican (*N*=79)**	**Test of Significance**
	N (%)	*N* (%)	*p*-value
Employment Status			
None	115 (60.9)	61 (77.2)	**.01**
Part-time	42 (22.2)	6 (7.6)	
Full-time	32 (16.9)	12 (15.2)	
Married (% Yes)	105 (55.6)	24 (30.4)	**.0002**
Poor (% Yes)	126 (66.7)	25 (31.7)	**<.0001**
High School Graduate (% Yes)	86 (45.7)	48 (60.8)	**.02**
Caregiver Sex (% Female)	181 (95.8)	74 (93.7)	NS
Child Sex (% Female)	63 (33.3)	32 (40.5)	NS
Ever Used CAM (% Yes)	134 (70.9)	65 (82.3)	.05
Currently Using CAM (% Yes)	103 (54.5)	56 (70.9)	.01
Use OTC Medications for Asthma (% Yes)	59 (31.2)	19 (24.1)	NS
Clinical Depression-Parent (% Yes)	45 (23.8)	34 (43.0)	.002
Clinician Rated Control			
Well-controlled	103 (57.2)	25 (36.2)	.01
Not well-controlled	64 (35.6)	35 (50.7)	
Poorly controlled	13 (7.2)	9 (13.0)	

Clinician Rated Severity Mild Intermittent Mild Persistent Moderate Persistent Severe Persistent	 32 (17.1) 63 (33.7) 75 (4.01) 17 (9.1)	 11 (14.7) 16 (21.3) 31 (41.3) 17 (22.7)	 .01
Controller Medication: Past year (% Yes)	141 (74.6)	67 (84.8)	NS
Controller Medication: Past month (% Yes)	131 (69.3)	62 (78.5)	NS
Controller Medication: Past 24 hours (% Yes)	109 (57.7)	50 (63.3)	NS
	Mean (SD)	Mean (SD)	p-value
# Family Members w/Asthma	1.24 (.73)	0.91 (1.09)	.02
Asthma Duration (Months)	67.94 (39.54)	88.46 (31.77)	<.0001
Caregiver's Age	35.47 (6.31)	38.42 (10.47)	.02
Study Child's Age (Years)	9.67 (2.15)	9.23 (2.23)	NS
# Years Caregiver Lived in US	14.05 (7.75)	33.88 (13.00)	<.0001
# Years Study Child Lived in US	8.39 (2.27)	8.23 (2.78)	NS
AIRS: Nature of Asthma Symptoms	2.74 (.66)	2.72 (.63)	NS
AIRS: Facts About Asthma	3.56 (.41)	3.58 (.34)	NS
AIRS: Attitudes re Medication Use	2.66 (.62)	2.73 (.56)	NS
AIRS: Treatment Expectations	3.07 (.59)	2.75 (.45)	<.0001
AIRS: Emotional Aspects re Medication Use	2.98 (.79)	2.86 (.71)	NS

AIRS: Total Score	3.10 (.36)	3.03 (.30)	NS
Parent-Provider Relationship	3.72 (.54)	3.78 (.55)	NS
Asthma Symptom Checklist (P-CASCL): General	5.98 (17.30)	58.42 (13.81)	NS
Asthma Symptom Checklist (P-CASCL): Panic-Fear	30.89 (11.88)	30.58 (12.24)	NS
Asthma Symptom Checklist (P-CASCL): Irritability/Hyperventilation	19.92 (8.10)	21.42 (8.00)	NS
Acculturation: Ethnic Society Immersion	3.23 (.35)	3.22 (.41)	NS
Acculturation: Dominant Society Immersion	2.98 (.39)	3.40 (.44)	<.0001
Asthma Trigger Inventory: Animals	0.91 (1.04)	1.30 (1.10)	.006

Based on the statistical data provided above, there are some noteworthy differences in some of the variables between Mexican and PR caregivers and their children with asthma. Compared to Mexican caregivers, PR caregivers are older, more likely to have a high school degree but be unemployed, less likely to be married or poor, have lived in the U.S longer, reported higher numbers of depressive symptoms, and reported greater dominant society immersion. The social network scores of PR caregivers were significantly lower than that found for Mexican caregivers.

PR caregivers also reported higher prevalence of asthma among family members and higher numbers of animal asthma triggers. Additionally, there is a higher percentage of PR who have used complementary alternative medication (CAM) and a higher

percentage that are currently using CAM than Mexicans. This can be reflected in the finding that PR compared to Mexican's have an overall decreased AIRS© treatment expectation than Mexican's and scored lower on the ACT questionnaire for both the child and parent.

PR children reported longer asthma direction, had a greater incidence of Emergency Room visits and hospitalizations in the past year, and PR children missed school at a higher frequency rate than Mexican children. Additionally, clinician rated control for PR children was more likely to be stated as not well controlled or poorly controlled, and there was a higher proportion of children classified as moderate or severe persistent by the clinician compared to Mexican children.

Research Questions Results

RQ 1

Research Question 1 examines the prevalence of lifetime and current CAM use in this sample of Latino parents and their children with asthma. This was done by chi-square analysis of the dichotomous Y/N variable.

Table 3: Lifetime CAM Use by Ethnicity

	No	Yes
Mexican	55	134
Row Percent	29.1%	70.9%
Column Percent	79.7%	67.3%
Puerto Rican	14	65
Row Percent	17.7%	82.3%
Column Percent	20.3%	32.7%
Total	69	199
Percent	25.8%	74.3%

$X^2=3.77$; $p=.05$

These results reveal that significantly more Mexicans have lifetime use of CAM than PR.

RQ1a. Does current CAM use differ by ethnicity?

Table 4: Current CAM Use by Ethnicity

	No	**Yes**
Mexican	86	103
Row Percent	45.50%	54.50%
Column Percent	78.90%	64.8%
Puerto Rican	23	56
Row Percent	29.1%	70.9%
Column Percent	21.1%	35.2%
Total	109	159
Percent	40.7%	59.3%

$X^2=6.02$; $p=.01$

Mexican caregivers are significantly more likely to currently be using CAM than PR.

RQ1b. Do parents report using CAM with (complementary) or instead of (alternative) their child's controller medications?

Thirty-eight percent of caregivers report using CAM plus controller medications (complementary CAM use) to manage their child's asthma and 19% reported using no treatments at all. Twenty-two percent reported using only CAM (alternative CAM use) and 22% reported using only controller medications.

Table 5: Composite CAM Usage by Ethnicity

	No CAM and no AI	AI only, no CAM	CAM only, no AI	CAM and AI
Mexican	42	44	38	65
Row %	22.2%	23.3%	20.1%	34.4%
Column %	82.45%	75.9%	65.5%	64.4%
Puerto Rican	9	14	20	36
Row %	11.4%	17.7%	25.3%	45.6%
Column %	17.7%	24.1%	34.5%	35.6%
Total	51	58	58	101
%	19.0%	21.5%	21.6%	37.7%

X^2=6.78; p=.08

Research Questions 2 and 2a

RQ2. Do parents' asthma illness representations predict treatment decisions (CAM and controller medication use) and clinician rated asthma control after controlling for caregiver depression and symptom perception?

RQ2a. Are there differences in treatment decisions and clinician-rated asthma control by ethnicity?

There is a trend for differences in the composite CAM variables by ethnicity. An alarming 19% of the total sample is not using CAM or controller medications and 22% are using only CAM for a total of 41%. Twenty-two percent report using only controller medications and 38% report using controller medications plus CAM.

More PR caregivers are using CAM plus controller meds to manage their child's asthma.

More Mexicans are not using any CAM or controller meds for asthma management.

Table 6. Multinomial Logistic Regression for Treatment Decision

Variable	Estimate	SE	95% CI	*p*-Value
Ethnicity	-.39	2.39	-5.08, 4.29	.87
Depressive Symptoms	.004	.01	-.02, .02	.72NS
Generalized Symptoms-Child	-.01	.01	-.03, .01	.17NS
Panic/Fear-Child	.01	.01	-.01, .04	.34
Irritability-Child	-.02	.02	-.07, .02	.25
Generalized Symptoms-Parent	-.02	.01	-.03, .001	.07
Panic/Fear-Parent	-.03	.02	-.06, -.002	**.04**
Irritability – Parent	.04	.02	.001, .08	**.04**
Asthma Illness Representation (AIRS)	-.41	.71	-1.81, .99	**.56**
Ethnicity*AIRS	.34	.79	-1.20, 1.88	**.66**

There is no main effect for ethnicity, child symptom perception, caregiver depression or illness representations. Higher caregiver panic/fear and irritability were significant predictors of no treatment being administered. A trend was observed for generalized

caregiver symptoms to also be associated with no treatment. There was no interaction of ethnicity and illness representations on treatment decision.

Table 7. Logistic Regression for Clinician-Rated Control

Variable	Odds Ratio	*p*-Value
Ethnicity	.75	**.08**
Depressive Symptoms	1.00	.81
Generalized Symptoms-Child	1.00	.66
Panic/Fear-Child	.96	**.02**
Irritability-Child	1.03	.20
Generalized Symptoms-Parent	1.01	.48
Panic/Fear-Parent	1.01	.70
Irritability -Parent	1.00	.91
Asthma Illness Representation	.48	.11
CAM/Controller Med Composite **No Cam/No Controller Medication** **Controller Medication Only** **CAM Only**	 1.23 .61 1.23	 .40
Ethnicity*CAM **No CAM/No Controller Medication-Mexican** **Controller Medication Only-Mexican** **CAM Only-Mexican**	 1.50 .62 2.11	 **.002**

*Reference groups=PR; CAM+Controller Medication; Not well-controlled asthma

There was a trend for a main effect of ethnicity on clinician-rated control with PR children more likely to be rated as not well-controlled. Higher panic/fear in children, but not their caregivers, was related to not well-controlled asthma. There was also a significant interaction of ethnicity and CAM use.

Chapter V

This chapter will summarize the study findings, draw conclusions, and offers recommendations and study implications.

Conclusions Among the entire sample, 74% have used CAM in their lifetime. Among those who used CAM, 67% of users were Mexican. Overall, 60% of study participants currently use CAM. Of those currently using CAM, 65% were Mexican. Of great concern is that 41% of the sample reports no controller medication use and 19% report no treatment at all and all of these children have persistent asthma that requires daily controller medication. CAM use seems to very persistent as evidenced by similar lifetime and current CAM rates. This demonstrates that people are not starting and stopping their CAM use; it is a treatment that they continue to use.

At least 60% of the study sample reported anti-inflammatory controller usage. However, it is unknown whether controllers are being used correctly and appropriately. For example, 62% of PR report controller usage (with or without CAM use), yet 64% of PR have clinician-rated asthma severity of moderate-persistent or severe-persistent (data not reported). On the other hand, 57% of Mexicans report controller usage, yet only 49% of Mexicans have moderate-persistent or severe-persistent asthma. This could be because PR are sicker from the start, and therefore are better at using controller medications in an attempt to keep asthma attacks at bay. More PR than Mexicans are using both controller medications and CAM, possibly in an attempt to control more severe asthma. PR could be

using their controller medications, but when the children are still sick on anti-inflammatory medications the parents are also trying CAM. It is also possible that PR are not using anti-inflammatory medications correctly and therefore they suffer from more severe asthma.

Interestingly, increased caregiver panic, fear, and anxiety were associated with greater likelihood of no treatment at all. It is possible that these heightened emotions interfere with their ability to appropriately observe their child's symptoms and render the appropriate treatment. Only child's panic/fear, however, was associated with clinician ratings of poor control. This is likely because children with poorly controlled asthma experience more symptoms, and therefore more fear and panic at their difficulty breathing.

Implications of Study

This study demonstrated that Mexicans and PR have different illness representations, CAM usage and pattern of use, and clinician ratings of asthma control. According to Braganza, Ozuha, and Sharif, only 18% of parents reported CAM use their healthcare provider (2003). It is important to understand illness representations and CAM, so effective communication and shared decision-making can occur. This study demonstrated that among Latino populations, CAM usage is very high and CAM should be discussed with families to ensure that asthma is being appropriately managed. According to Adams et. al., 59% of parents of asthmatic children believe that CAM usage is just as

effective and conventional medications in controlling their child's asthma (2007). HCPs who are familiar with and sensitive to illness representations and care needs of diverse groups can play a decisive role in improving health outcomes of patients with asthma by heightened awareness of and respect for cultural differences among the children and families they interact with.

Recommendations

As asthma is chronic yet episodic in nature, the child's ability to correctly identify asthma symptoms and the family's ability to enact an appropriate symptom management plan is critical in the optimal management of this disease and dependent on the adherence to the medication regimen prescribed (McQuaid et al., 2007). The health care provider's (HCP) ability to understand and appreciate their patient's different illness representations will improve patient-provider relationships and likely improve asthma management. HCPs should be regularly asking their patients about CAM use, since it is highly prevalent and impacts a patient's asthma management plan. Further research about HCPs understanding of CAM and its prevalence, usage, and implications will likely improve patient care and outcomes.

Further investigation of asthma symptom perception would be highly beneficial. It is still unknown how to change a patient's perception of asthma, such as the fact that it is a chronic disease rather than acute. If patients had a true, physiological understanding of

their disease the asthma could be more promptly and appropriately treated; CAM use would likely decrease and controller medication use would increase. A study done in a school or community setting would be very beneficial to understand asthma perception, and how to correct perceptions that are incongruent with the medical model.

Limitations

The biggest limitation for this study was that it was a secondary analysis of data already collected. Another limitation is that we do not know if the reported controller medication use meant the medication was being used appropriately and according to the prescription.

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